FOR IMMEDIATE RELEASE

HUMAN RIGHTS AUTHORITY-SPRINGFIELD REGION

REPORT 14-050-9017
Transitions of Western Illinois

INTRODUCTION

The Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission opened an investigation after receiving complaints of possible rights violations in the care provided to a resident in Transitions' Community Integrated Living Arrangement (CILA) in Quincy. Allegations were that the facility has not provided the resident with adequate and humane care and services pursuant to his individual services plan, true purposes and nature for record disclosure were not specified or explained to his guardians, false information was entered in his record and the program has no policy or procedure for entering record disputes, which, if substantiated, would violate protections under the Mental Health and Developmental Disabilities Code (405 ILCS 5), CILA and Medicaid Community Mental Health Services Program Rules (59 Ill. Admin. Code 115 and 132) and the Mental Health and Developmental Disabilities Confidentiality Act (740 ILCS 110).

Transitions offers a variety of mental health and developmental disability services to people of all ages around Adams County. The mental health side of its program includes community based counseling for about three hundred-fifty clients, ten-unit independent living apartments and a fifteen-bed group home or CILA.

The HRA team visited Transitions' main office and discussed the matter with program representatives. Relevant policies were reviewed as were sections of the resident's record with proper authorization.

COMPLAINT SUMMARY

According to the complaint the group home has been trying to discharge this resident for some time now and is not providing psychiatric services as planned. The guardians recently changed psychiatrists and the home's manager had them sign a release saying it would allow them to communicate with the new provider and get a much needed Risperdal shot. The manager reportedly told them they could have their own nurse give the shot if prescribed but after the guardians signed the release said they could not; she never explained what the release covered and said it was just for the injection. After one visit the guardians received a letter from the new psychiatrist stating that upon review she decided not to treat the resident because of his

complex conditions. They followed up with an administrator at the psychiatrist's office who allegedly claimed that this was based on troubling information in the resident's record. It was therefore suspected that the home "blackballed" them, giving inaccurate and inflammatory information about lunging and being aggressive, much more information than was needed for a shot. The resident was hospitalized around this time and remained without a community psychiatrist.

FINDINGS

Interviews

On the first issue, providing psychiatric services as planned, the staff explained to us that this CILA resident has a current one-year lease under Housing and Urban Development. The lease expires January 2015 and there is no limit on holding the apartment while he is away or hospitalized. Typical case management services are provided under Rule 132: general daily supports and encouragements, prompting for taking medications and for maintaining hygiene, monitoring medication use, getting him to appointments and keeping in touch with the psychiatrist, for example. Although this resident is likely the most ill they have at the moment and they have discussed with his guardians the need for more intensive care, there are no formal plans in place for discharge. They said about a year ago the resident started eloping and they have growing concerns for him being out in the community. In one instance the police found him standing in an intersection and brought him home. Consequently, they brought up the need for a higher level of care with the guardians although it has not been received well. Recently the guardians changed psychiatrists from the one the home contracts with and whom the resident had seen for seven or eight years; he was one of two who treat their adult residents. The guardians made arrangements for an initial appointment with a new psychiatrist, and provided they allow communication, it was intended for the service plan to continue supporting him in getting to appointments and monitoring any prescribed medications and progress. The home's manager prepared a release of information for the new provider, which one of the guardians signed.

Regarding that release, the manager said it was necessary to coordinate care with the new psychiatrist whom the guardians chose. She believes the release was thorough in order to do that, that she explained the release's purpose and that the guardian seemed to understand what she was signing. It was not completed just for a Risperdal shot but to manage any psychotropic medication use as might be prescribed and to share information as needed.

The staff said that records were never shared with the new psychiatrist. The home's manager attended the first appointment with the resident and his guardians in early April and then later prepared the release when it was thought that treatment would continue there. She said the resident tolerated the appointment well for about fifty minutes. The psychiatrist asked her and the guardians a lot of questions about his history; a follow up appointment was set, and later the manager spoke briefly with the psychiatrist's nurse on completion of the release. There was no other communication or information shared. Shortly after that the guardian rescinded the release, well before the next scheduled appointment. The HRA was told that not only was no other information provided, there was nothing inaccurate or inflammatory entered in the resident's record. There was an incident considered aggressive a few months earlier where he charged at one staff member in the home. The staff involved described to us what took place and

said he was doing "reps" or taking two steps forward and then stepping backward repeatedly, which is common for him. Only this time he was getting too close while doing that and eventually started to run at her. She felt threatened and had to run out of the office herself. A summary of this incident was included on a petition that led to his hospitalization. A copy of the petition was not kept in the home's record, but they said there was a chance the behavior could have been referred to as lunging. However phrased, there was nothing inaccurate or inflammatory.

We followed up with the hospital administrator who allegedly told the guardians about troubling information from the record. She reported to us that they received no records at all from the home. The psychiatrist's office manager was also interviewed and she said she was present during the resident's visit and that he was very disruptive. He paced back and forth and used profanity repeatedly while children were present. His parents had to calm him down. The psychiatrist based her decision not to treat him on her own observations and assessment at that time, concluding that she could not provide the level of care he needed.

On whether the program has a process for entering record disputes, the staff said they do as part of their inspection and copying records policy. A written dispute is to be attached to the corresponding portion of the record and will accompany any authorized disclosure. They said that the guardians in this case have not requested to revise documentation or to add content disputes at the time of our inquiries.

Records

A new individualized service plan developed in February 2014 states that it is to be revisited in April 2014. The multiaxial diagnostic scale shows a low 20 score for the global assessment of functioning. A higher level of care is an identified need. Among goals and objectives to monitor medication use and manage symptoms and lab work, the staff agree to work with the resident as his guardians arranged psychiatric services and that if medications are prescribed, to support and encourage him in taking them. Specific steps are outlined to encourage medication compliance, and to maintain appropriate hygiene and weight. The manager will attend all appointments and participate in physician visits. They are to alert the guardians of any problems and if the resident leaves the CILA. Participant signatures include those of both guardians.

A release of information dated April 11, 2014 authorizes disclosure to the hospital where the new psychiatrist is employed. Items for release include intake and discharge records, medical and psychiatric records, treatment recommendations and assessments. Added in handwriting is that information may be released to coordinate receiving psychotropic medication. Continuity of care is checked as the disclosure's purpose. It is valid for one year and signed by the manager and one guardian. That guardian wrote on the release April 21 that the authorization is rescinded.

The case manager's progress notes state that she attended the initial appointment with the new psychiatrist, the resident and his guardians on April 2. According to her, they were all asked

questions about medical and mental health history, symptoms, challenges, stressors and family. The case manager relayed historical information from the CILA, including non-compliance with medication and issues with eating, hygiene, isolating and repetitive behaviors. The psychiatrist suggested bribing the resident with rewards for taking meds and a follow up appointment was scheduled. Nothing was ordered. The appointment occurred on the heels of discharge from a state hospital. Included in the record is a petition for medications from admission in February 2014 and a discharge summary from that hospital on April 2, both stating that the resident had been hospitalized for reportedly lunging at a staff member in his home and making threats, referring to the January incident. The HRA reviewed the staff member's incident report regarding the January incident. As she described, she wrote that the resident was doing reps in the common area and then in the office, that he stood very close to her, stared at her, moved closer, put his head between his legs and then quickly stood up straight. This went on for a time until he charged at her. She ran out the back office door and closed it, then observed him through a window as he stared at a wall, eventually moving toward his room, pacing down the hall while yelling. The incident report refers to intense reps and charging, not lunging specifically. However, a pre-screening agent who completed a uniform screening and referral form for the hospital admission wrote that he had lunged at staff in his group home.

Progress notes continued on April 4 when the manager met with the guardians for input on ways to get the resident compliant with medications. On April 9 and 11 she recorded conversations with one guardian about getting Risperdal shots, storing them and whether nurses from the hospital could come to the home to administer them. The manager stated that they would comply with any physician's order. Later on the 11th the manager spoke with the new psychiatrist's nurse and asked, per the guardian, whether she could come to the CILA to give the shots, if two male nurses could or if they could store the medication at the hospital and give them during his appointments. The nurse responded that she had already explained to the guardian that they could not for various reasons. There was no further documented contact with the psychiatrist's office. Another incident causing the next hospitalization was recorded on April 15. The case manager's entry states that she called the guardians to the home after the resident soiled himself. In their presence he became fixed in his repetitions and suddenly lunged forward, had a difficult time walking and then returned to his reps. The guardians left and the behavior continued and the resident would not respond. She called the guardians who agreed with having him evaluated at a hospital. The manager's documentation in this instance referred to lunging, deterioration of functioning and increase in psychosis.

The HRA also reviewed a few items relating to the emerging crisis, new psychiatrist and the exchange of information. There is a letter from about a year ago from the program to the guardians expressing their concerns for the resident's condition. It states that they find their services are no longer appropriate for his needs, that they intend to discharge him but wanted to work with them on planning that. Several items of concern were outlined. The HRA received three documents for review from the guardians. The first is a copy of the January petition for involuntary admission. In it the staff member involved in that incident asserted that the resident ran at her and displayed aggressive behavior; the word lunging is not used. The second is an April 11 letter from the new psychiatrist in which she states that she decided to not proceed with further outpatient treatment based on her assessment of the resident and his complex condition. The letter states that he needs more acute therapy than what she was comfortable providing and

includes referrals to other agencies. The third is the psychiatrist's notes on the April 2 appointment in which she wrote that the resident was accompanied by his guardians; there is no mention of the case manager being present. She described the resident as a poor historian and that she relied on the guardians for information. "He has a history of lunging and threatening staff at the…group home where he lives. However, they deny any physical altercations." The home's record includes a May 16 letter from the program to the guardians asking for authorization to share information with other providers, all of which had been revoked, in order to appropriately arrange for the resident's return to the CILA after hospital discharge. A May 21 letter in response which states that in the guardians' view, the appointment went well but they received word that the psychiatrist would not continue treating because of information in the records provided by Transitions. They had serious reservations about record contents and would hold off on authorizing any further disclosures until that is resolved.

Nothing in the record references the release of information to other agencies, content disputes or grievances on the guardians' behalf. It does contain a request to copy/inspect records, signed by one of them in January, and a list of the records that were copied is attached. A consumer rights and responsibilities statement provided to all consumers and their legal representatives includes the right to review records and to request amendments according to policies.

The resident was discharged from the state hospital and he moved into a new residential facility at the time of this writing.

CONCLUSION

Complaint: the facility has not provided with adequate and humane care and services, pursuant to his individual services plan.

Transitions' service delivery policies require all consumers to have initial assessments, the results of which will drive whatever is provided (4.01). Individual treatment plans are developed and modified along with participation of the treatment team including the consumer, any family or guardian, and the CILA staff. They meet every six months to review plans but more often as necessary to meet changing needs (4.02).

The Administrative Code for community mental health services states that case management shall include assessment, planning, coordination and advocacy based on client-centered consultation, any of which the client may refuse (59 Ill. Admin. Code 132.165). Medication services must be provided on order of a physician employed or contracted with the provider (59 Ill. Admin. Code 132.150).

Under the Mental Health Code, "A recipient of services shall be provided with adequate and humane care and services, in the least restrictive environment, pursuant to an individual services plan. The plan shall be formulated and periodically reviewed with the participation of the recipient to the extent feasible and the recipient's guardian…." (405 ILCS 5/2-102a). Adequate and humane care and services are defined as those reasonably calculated to prevent a

decline in one's clinical condition so that he or she does not present an imminent danger. (405 ILCS 5/1-101.2). All adult recipients and their guardians have the right to refuse any mental health service (405 ILCS 5/2-107).

The question here is whether Transitions continued to provide services as planned, namely psychiatric, when the resident's guardians chose another provider. The program contracted with a psychiatrist who followed this resident for seven or eight years and supported him in monitoring his medications and progress, all of which continued when the guardians chose to end the relationship with the contracted psychiatrist and selected another. The newest service plans directed that the resident still be monitored on a daily basis, assisted in getting him to the new provider's appointments and to communicate progress with the provider and guardians, the documentation of which shows they proceeded as planned to the extent the guardians approved. The complaint is not substantiated.

Complaint: true purposes and nature for record disclosure were not specified or explained to his guardians.

A policy covering clinical records and the release of consumer information states that anything sent from Transitions must be initiated by an appropriate release, based on a completed and specific authorization for release form as governed by the Confidentiality Act (3.01).

The Confidentiality Act allows the inspection, copying and release of record information upon recipient or guardian request. Every consent form shall be in writing and shall specify the purpose for which the disclosure is to be made and the nature of the information to be disclosed. Only information relevant to the purpose may be disclosed. A copy of the consent and notation of any action thereon must be entered in the record (740 ILCS 110/4, 5).

The complaint states in summary that the release to provide information to the new psychiatrist was thought to be for a shot, not to share a complete record and that the release was not thoroughly explained to the guardian who signed it. Although the HRA does not discount the claim, the staff who completed and witnessed the release reported to us that she did explain it and that the guardian seemed to understand what she was signing. The release itself is thoroughly completed, with checks on every relevant item to be disclosed and the purposes for disclosure as indicated in writing, all pursuant to program policy and the Confidentiality Act. A violation is not substantiated.

Complaint: false information was entered in his record.

A policy for documentation in resident files states that records are to be complete and that entries are validated with signatures and titles (3.16). Progress notes and behavioral reports are to be documented and entered within twenty-four hours of contact or incident (3.01).

The CILA Rules require the same in that all entries are to be legible, dated and authenticated by the signature and title of the person making the entry (59 Ill. Admin. Code 115.320 h, A).

Per the Mental Health Code, every petition, certificate and proof of service shall be executed under penalty of perjury as though under oath or affirmation (405 ILCS 5/3-203).

The assertion is that Transitions intentionally provided inaccurate and inflammatory information to the new psychiatrist in order to "blackball" the resident, leaving him without a provider and consequently without services at the group home. With this issue again the HRA will not dispute either side's recollection of events or how either chooses to describe them. We base our findings on statements and supportive documentation, which we found in this case to provide no evidence of wrongdoing. Authentic documentation and portrayal of all recipients is profoundly important as it follows wherever they go and influences the course of services. The staff whom we met at Transitions agreed. The term "lunging" along with other references to being aggressive were specifically identified in the complaint as inaccurate and inflammatory descriptions. According to the staff, their documentation surrounding the events leading to two hospitalizations and the meeting with a new psychiatrist reflected what they observed. A report about the first incident in January detailed how the resident acted more aggressively than usual and how he ran at the staff member. Her petition for admission that followed characterized the same. It is noted that on transfer from the local hospital to a state hospital, the screening agent who completed a referral form repeated this information but by using the term "lunging" instead. This is first sight of the term in the records we reviewed, and, admission, discharge and petitioning records from the admitting hospital include lunging from there. Transitions is not responsible for that documentation. It appears again in the new psychiatrist's April appointment note where she described it as behavioral history, based on interviews with the guardians, which is curious. Also curious is the fact that the case manager said she was at the appointment and provided information but the psychiatrist reported that only the guardians were there and that she relied on them. But both providers deny releasing or receiving Transitions' records. Perhaps the psychiatrist's description of history and the hospital administrator's statement that the record contained troubling information was based on their own records since the resident was a previous patient there, and, since the former contracted psychiatrist practices there as well. This is all speculative. Finally, the case manager begins to use the term lunging along with descriptors of intense or unusually aggressive behavior and deterioration of functioning in her notes leading to the next hospitalization, but after the visit with the new psychiatrist. Based on the trail of documented information provided, the complaint is <u>not substantiated</u>.

Complaint: the program has no policy or procedure for entering record disputes.

According to Inspection and Copying of Clinical Records policy, should an individual find incorrect or misleading information in their clinical record, they have the right to submit a written statement into their record or request modification.

The policy follows the Confidentiality Act, which states that a recipient or guardian may submit a written statement concerning any disputed information, which shall be entered into the record. The statement is to accompany any disclosure of that part (740 ILCS 110/4 c).

Transitions' policy in place for entering record disputes satisfies the right under the Confidentiality Act. A violation is <u>not substantiated</u>, and the following suggestion is offered:

Suggestion

Include in policy the guardian's ability to amend/dispute record contents along with the individual.